Culture and the Understanding of Advanced Heart Failure: A Mixed-Methods Systematic Review

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Abstract

Background: Cultural values and beliefs influence understanding of health and illness, but we do not know their impact on patients' understanding of advanced heart failure.
Aims: We explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.
Method/Data Sources: In this mixed-methods systematic review, we systematically searched MEDLINE, EMBASE, CINAHL, Scopus, Web of Science, PsycINFO, and Cochrane CENTRAL with no time limits using relevant MESH terms and keywords. Papers were themed, synthesised, and grouped into domains. The theoretical framewok PEN-3 was used to underpin the findings.
Findings: We screened the full-text of 194 studies and found 13 articles eligible; of which 6 were qualitative studies, 5 quantitative and 2 were mixed-method studies. In these studies, patients' understanding of, and response to, symptoms were strongly linked to cultural beliefs. Patients from Eastern and Middle Eastern countries somatised symptoms more than those from Western cultures. Patients from Western cultures reported higher symptom distress scores. Peoples' cultural beliefs about health and disease inform lay knowledge of heart failure diagnosis, causes, treatment and self-management and influence their healthcare decisions and behaviours.
Conclusion: We found that health care practice and research in heart failure has not previously been influenced by culture. People with heart failure and their family members could be helped better by health care practitioners if their cultural values and beliefs were integrated into health care practice and policy. We argue that this is essential for the successful development of culturally competent care interventions for all people with advanced heart failure.

Keywords
Culture, Heart Failure, Comprehension, PEN-3 Cultural Model.

Implication for practice:

Problem or Issue

- The impact of culture on chronic disease and disease understanding is poorly understood, particularly for heart failure.

What is Already Known

- Healthcare systems do not recognise the intersection of culture with chronic disease and its impact on peoples' understanding of chronic diseases. A better understanding of the impact of diverse cultural health beliefs would overcome this failure and allow provision of culturally competent care.

What this Paper Adds?

- This study provides robust insights to the varying needs of people with heart failure from different cultures and will help with development of culturally tailored supportive interventions.

1. Background

Heart failure affects 1–2% of the population (Piotr et al., 2014), with over 26 million patients affected, globally (Bui, Horwich, & Fonarow, 2011; Piotr et al., 2014). The prevalence increases steadily up to 10-13% with advancing age (Conrad et al., 2018). In the UK, 1-2% of National Health Service (NHS) expenditure is spent on heart failure management (Cowie, 2017); and 60–70% of this on patient hospitalisation costs.

Around 10% of people with heart failure will progress to advanced/end-stage heart failure (Deng, Ascheim, Edwards, & Naka, 2002; J. C. Fang et al., 2015; Xanthakis et al., 2016). Advanced heart failure is defined as 'a primary diagnosis of chronic heart failure under optimal therapy with persistent symptoms or NYHA Class III-IV symptoms with frequent hospitalisation during the previous 12 months' (Abouezzeddine & Redfield, 2011). Patients reaching this stage often have burdensome refractory symptoms and poorer quality of life, which necessitates a collaboration between Cardiology

and Palliative care (Sobanski et al., 2019). Palliative care (IAHPC, 2018) benefits patients with advanced heart failure (Conrad et al., 2018; Crespo-Leiro et al., 2018; Jaarsma et al., 2009) by relieving suffering and enhancing the quality of life for both patients and their families (McIlvennan & Allen, 2016).Increased mobility of global populations has created its own Western and Eastern cross-cultural challenges, particularly when attempting to provide culturally appropriate health and palliative care services for multi-ethnic minority groups within mainstream western health systems

Culture is known to affect people's health and health-related outcomes (Kagawa-Singer, 2011; Kwabi-Addo, 2017; Suurmond, Hudelson, & Dogra, 2015), but little is known about the influence of culture on chronic disease and disease understanding. Research is needed into how the understanding of advanced heart failure affects

patients' and family members' heart failure beliefs, treatment preferences, expectations about disease and help-seeking behaviours at crucial points during the treatment process for heart failure. This research is vital for the development of culturally competent interventions to improve healthcare provision.

2. Aims

The purpose of this review is to explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.

3. Methods

A mixed methods systematic review design was used, incorporating a combination of approaches for data extraction, analysis, and synthesis. This approach was deemed a suitable method due to the heterogeneity of the primary research on culture and heart failure. The review was conducted in accordance with the PRISMA checklist (Liberati et al., 2009). The protocol was registered and published on PROSPERO (CRD42018084612).

3.1. Search strategy and study selection

The review question was developed using an adapted tool from the PICO (Cooke, Smith, & Booth, 2012) and SPICE (Booth, 2006) frameworks. To ensure rigorous search strings, a combination of text words and medical subheadings were used, where applicable, for each search string. Following the recommendations of Brunton, Stansfield, Caird, and Thomas (2017), four search strings were iteratively tailored and refined in the aid of the adapted tool to address the review question (Appendix 1). Due to scarcity of evidence on the role of culture in shaping different understanding of disease, we piloted our search using broad search terms on MEDLINE though OVID. Thereafter, the established syntax was extended to EMBASE, CENTRAL, CINAHL, PsycINFO, WOS and Scopus in January 2018 with no date restrictions (Figure 1).

3.2. Eligibility

All published and unpublished qualitative, quantitative and mixed-method studies that focused on at least one of the outcomes of interest were eligible for inclusion. Studies using primary or secondary data were eligible, as long as they provided more information or reported different results.

Studies published in English that identified participants to be adults (>18 years) with either advanced heart failure, or family members of someone with advanced heart failure, or health professionals who have provided care for someone with advanced heart failure were included.

3.3. Theoretical framework

Health or illness is culture-specific, and culture is a critical determinant of human health outcomes and shapes health behaviours. The PEN-3 model situates culture at the forefront of health determinants and healthcare interventions (Airhihenbuwa, 1990; 1995; 2007; Airhihenbuwa & Webster, 2004). Figure 2 presents the three interconnected interrelated PEN-3 domains of inquiry. Each domain has three subcomponents assembled to form the three PEN acronyms and are assumed to represent the overall impact of culture on that domain.

We used two components of PEN-3 Model; the Relationships & Expectations and Cultural Empowerment domains of the model (Figure 2) to guide our search strategy and data synthesis (Figure 3).Themes were constructed solely based on the extracted data without reference to the PEN-3 model constructs. The two constructs were used as a guide to identify and assess all forms of cultural impacts in each study. The cultural impact themes were further evaluated using the concepts of perceptions (beliefs and values); enabler (factors barrier or hinder change) and nurturers (the role of social support) in the relationships and expectations domain. Then, we categorised the data under the constructs that reflect the form of impact (positive, existential or negative).

3.4. Data extraction

We developed our own data extraction form to best match the review aims in accordance with robust systematic review guidance (Higgins, 2011). The form was piloted for feasibility by the two authors, (BA) and (BJ). Data extraction was carried out by (BA) and confirmed subsequently by two reviewers (BJ) and (KH). The data extraction was conducted in two stages. First, we extracted data on study authors and year, methodology, methods of data collection, sample and population characteristics, and heart failure severity and the impact of culture (Table 1). Second, data related to the cultural impact were subsequently summarised using the PEN-3 cultural model (Table 2). The use of assessment properties of PEN-3 model resulted in the cultural findings being framed and organised to centralise culture at the core of intervention development (Figure 3). Table 3 set out the findings of additional analysis we have undertaken by cross-tabulate themes with component and subcomponent of the PEN-3 model.

3.5. Quality assessment

This literature synthesis included quantitative, qualitative, and mixed methods research papers; we used one quality assessment tool to fit all study typologies. To ensure consistency we adopted the Mixed Methods Appraisal Tool (MMAT) (Pluye, Gagnon, Griffiths, & Johnson-Lafleur, 2009), for use with the most common types of empirical studies. One of the reviewers (BA) evaluated the 13 included studies independently. Both other authors (BJ) and (KH) reviewed and assessed each paper for quality assurance. All studies were ranked according to the achieved score and number of criteria fulfilled. Studies were classified into a low, moderate and high quality based on the MMAT criteria, along with the quality of reporting and reviewers' critiques based on

results. Quality level is presented in Table 1. These scores informed the data synthesis process.

3.6. Synthesis of results

The hybrid design to synthesise results (Sandelowski, Voils, & Barroso, 2006; Whittemore & Knafl, 2005) allowed the grouping of data into findings by domain rather than by different research methodologies (Sandelowski et al. 2006) as shown in (Figure 3). Descriptive thematic analysis was utilised for qualitative and quantitative data. We analysed data then synthesised findings according to the five stages of the integrative synthesis proposed by Whittemore and Knafl (2005). Line-by-line data coding and grouping were conducted according to the domain. These codes were evaluated and compared within each domain. Qualitative and quantitative data were combined using the integrated design synthesis of mixed-methods synthesis. (Sandelowski et al., 2006). The integrated design was appropriate as it allowed synthesising and assimilating quantitative and qualitative data together to explore the type, size, consistency of the cultural impact. Data comparison, by coding and summarising data related to aspects of influenced domain on understanding of advanced heart failure. Data was also compared within similar data sets. The conclusion and verification stage involved classifying themes according to their relationships with the understanding of heart failure. All authors have independently analysed data and then verified collectively. Three themes were constructed independently of the model constructs and solely by scrutinising the information from the primary resources constructed themes were then mapped onto the model.

Using the PEN-3 model we examined the cultural values and beliefs held by participants and that affected their their understanding of heart failure, ranging from positive to negative. (Appendix 1). This acheived the first aim. The other two

subconstructs were employed to achieve the second aim. Themes were cross checked with the included studies by the review team to ensure the coherence and consistency on the issues related to the cultural impact across the analysis phase to enhance credibility and reliability of the review findings.

4. Results

4.1. Study selection

The scientific and grey database searches retrieved 5977 citations; titles and abstracts were screened using Covidence systematic review software (www.covidence.org). To avoid selection bias, BA, BJ and KH independently reviewed these articles. While 11 articles fully met the inclusion criteria for our study, an additional two papers were identified through citation chaining and electronic hand searching of the European Journal of Cardiovascular Nursing and European Journal of Heart Failure from January 2015 to March 2018. The screening process is illustrated in Figure 1.

4.2. Study characteristics

Thirteen articles published between 2002 and 2017 were reviewed. Table 1 reports these numbered articles. Six studies were qualitative (Articles 2; 4; 5; 10; 12; 13), five quantitative (Articles 1; 6; 7; 9; 11) and two mixed-method studies (Articles 3 and 8). Most studies were conducted in Western countries (n=7) (Articles 1; 2; 3; 6; 7; 8; 12). Most studies considered patients only (n=10), two studies included caregivers with patients and one paper only studied caregivers (Article 4). Dyads of patients and their caregivers were in another four studies (Articles 2; 5; 10; 12). None of the studies considered the clinicians' perspectives. Eleven studies collected data fully or partially in hospital settings (Articles 1; 3; 4; 5; 6; 7; 8; 9; 10; 11; 13).

4.3. Review domains

The constructed themes can be integrated into a layered onion model (Figure 4). The diagrammatic model depicts the multi-layered interrelationships between cultural beliefs and values and the understanding of advanced heart failure at different levels or layers. At the centre of the onion, the coloured tiles, are the main themes, which impact all other layers. Firstly, the influence of culture on lay knowledge and understanding of all aspects of heart failure. Secondly, emphasising culture as a major component of the way advanced heart failure symptoms are perceived and grouped. Thirdly, cultural norms and values that could negatively or positively be associated with self-management behaviours. The middle layer represents the way patients conceptualise the collectively agreed value and beliefs by the community. Therefore, a deeper understanding of this layer would guide and to a certain extent provide explanations on how multiple cultural milieus, along with other factors, interact to produce unique health decisions and behaviours. The outer layer shows the explicit influences of the culture on the HF understanding.The process of cultural influences on understanding was seen as iterative and ongoing. The three constructed themes all overlapped. Inconsistencies between patients own beliefs and health recommendations restrict, the understanding of disease and, the adoption of certain healthy behaviours.

4.4. Lay heart failure knowledge, beliefs and perceptions

Several studies showed that most patients lack a clear understanding of what heart failure is (Articles 1; 4; 6; 10; 12), why they developed heart failure (Articles 10; 12), and the implications of heart failure diagnosis (Articles 1; 6; 10; 12) (Table 1). For instance, one-third of the enrolled subjects, and almost two-thirds of Asian patients were not aware of their heart failure diagnosis (Article 6). Patients and their families appear to define and correlate heart failure in different ways across cultures; none of

these was close to biomedical explanations (Articles 3; 6; 8; 10; 12). The research evidence demonstrated that most non-Western patients consider families, friends and traditional healers as their main sources of heart failure knowledge. Interestingly, conversely to that, they also considered healthcare professionals to be the main sources of information during the advanced stages of disease (Article 1; 3; 4; 6; 7; 10; 12).

Patients with advanced heart failure and their families acknowledge that cultural beliefs shaped how they managed their chronic illness (Articles 4; 5; 8; 10; 12; 13). Markedly, this cultural appreciation also affects perceived control over the patients' condition (Article 6), self-care knowledge (Articles 3; 5; 8; 10; 12; 13); treatment preferences and decisions (Articles 2; 5; 8; 10; 12; 13) and family caregiving roles during the advanced, end of life stage (Articles 4) (Table 1). People frequently ascribed patient struggles with having a "bad heart" due to supernatural assumptions such as "God's will" (Article 12), stressors (Article 3), and devil spells or bewitching (Article 10). This cultural misconception led patients to continue worshiping, accepting distressing symptoms or practising stress reduction techniques, though these were not considered as self-care but their normal cultural practice (Articles 3; 4; 5; 6; 8; 10; 12; 13). This represents another distinct understanding of disease that is directly linked to cultural health beliefs. Also, lay cultural knowledge was found to affect the acceptance of treatment. One of the studies (Article 2) proposed the influence of the cultural milieu on decisions, behaviours and, therefore, post-treatment experience with left ventricular assistive devices. These influenced beliefs on treatment decisions were particularly seen as important for those in low socioeconomic groups (Articles 1; 3; 8; 10; 12; 13).

Our synthesis demonstrates that lack of understanding led family caregivers to rely on cultural norms when providing care to their loved ones (Articles 2; 4; 5). It was clear

that being ignored by the healthcare system, and sometimes other family members, further aggravated the role ambiguity and state of uncertainty (Articles 2; 4). Caregivers were found to be assisting other family members rather than carrying out “caregiving responsibilities” (Articles 4; 5). For example, in Article 4 the caregiver’s role was attributed to cultural and religious beliefs (i.e. Allah-centred caring). This culturally-bounded understanding of caregiving confirms the results presented by Article 12, eight years previously in a similar culture.

4.5. Understanding symptoms, reporting and clustering

The studies suggested that patients’ understanding of symptoms, and consequently the way they responded to them, were strongly linked to their own cultural and personal beliefs (Articles 3; 5; 6; 9; 10; 11). In people with heart failure, symptoms were subjectively understood and reported and derived from patients’ cultural milieu (Articles 3; 6; 9; 10; 11). The more advanced the heart failure, the more likely it is for patients to have serious symptoms. However, patients were reluctant to report symptoms as they needed to be legitimised and consistent with the culture-specific definition of severe symptoms. For instance, some African cultures legitimise abdominal or leg swelling as serious symptoms that may, stop people from working, or require seeking help (Articles 3;10).

The understanding of symptoms and how symptom clusters across cultures were reported in two studies and were contradictory to each other (Articles 9; 11). It was clear that there was a tendency within each culture to report similar types, patterns and clusters of symptoms. However, contradictions were found comparing the variety of Eastern and Western cultures. With regards to physical symptoms, the ranking orders of physical symptoms were relatively similar across different cultures but not symptom severity scores. However, psychological symptoms were perceived differently and

subjectively across cultures (Articles 9; 11). Patients from Eastern cultures may have delayed symptom reporting, a lower ability to recognise changes in psychological symptoms, and underestimated severity of disease compared with patients from Western backgrounds (Articles 6; 9; 11).

In Article 9, symptoms were identified and labelled according to type, and demonstrated that the Physical and Emotional clusters were mostly agreed upon across cultures. However, Article 11 describes some differences triggered by cultural beliefs and values, in which symptom labelling was based on symptom intensity. For instance, a higher symptom distress score was reported by patients from Western compared to Eastern cultures for 75% of symptoms. The symptom clusters in the Eastern cultures differed in terms of the number of classes and their composition. The influence culture has on the understanding of psychological symptoms, such as depression, was more evident in the Western cultures and less so in Eastern cultures. Eastern cultures were also more likely to ignore psychological symptoms and to perceive their physical symptoms as less severe. Unsurprisingly, the order of the distress code of the symptoms was similar across cultures (Articles 9; 11). These findings confirm that culture shapes the decisions of patients with advanced heart failure when monitoring, identifying, evaluating and linking symptoms to heart failure and how they respond to them.

4.6. The understanding of heart failure self-care

The culturally coined beliefs on heart failure self-care were salient features of determining the ability of non-Western cultures to adhere to self-care practices. Our results demonstrate the fundamental role of family's and friends' understanding, and therefore support, in enhancing heart failure self-care among traditional cultures (Articles 3; 8). Nevertheless, the understanding of self-care is defined by culture, and

adherence to and performance of self-care are moulded by other co-impacting interdependent factors such as age, ethnicity, religion socioeconomic status and linguistic factors in traditional societies. Further, these factors have the potential to reform cultural influenced beliefs toward self-care. The problem with self-care is two-fold. Patients are not only not adhering to self-managing their disease, but also developing a blasé attitude toward change, even if this was followed by worsening symptoms or rehospitalisation (Articles 1; 3; 5). This was also found in patients with advanced heart failure (Article 13). For instance, cultural dietary habits, especially for people from low incomes were problematic; people found it difficult to reconcile changing to a cardiac diet or monitoring salt and fluid intake (Articles 3; 5).

In terms of self-care, cultural impacts were viewed to be explicit as enablers and implicit as barriers to self-care practices. Despite the positive responses about exercise, most participants were neither exercising nor aware of the use of exercise in heart failure rehabilitation (McCarthy, Katz, Schipper, & Dickson, 2015).

Similarly, a sense of contradiction was noted within certain cultures regarding adherence to prescribed medications, mainly when patients show admiration and gratitude that was not necessarily reflected in their behaviours (Artinian, Magnan, Christian, & Lange, 2002; Dickson, McCarthy, Howe, Schipper, & Katz, 2013; Jiang, Wu, Che, & Yeh, 2013; Lip et al., 2004; McCarthy et al., 2015; Namukwaya, Murray, Downing, Leng, & Grant, 2017; Pattenden, Roberts, & Lewin, 2007; Rong, Peng, Yu, & Li, 2017). For example, in African American culture, life-long adherence to medication was considered an essential step for living. However, more than two thirds of participants from the same culture had not correctly answered the heart failure knowledge questions about their medications (Artinian et al., 2002). Also, the longer heart failure symptoms persist, the less likely patients are to trust medications,

particularly when biomedical treatment is no longer sufficient to relieve suffering during the advanced stages (Jiang et al., 2013; Namukwaya et al., 2017; Rong et al., 2017).

Most cultures appreciate the importance of family and extended kinship bonds in enhancing the understanding and performance of self-care (Articles 3; 8). When people have a good understanding of their disease with good health literacy, family played a positive role in enhancing positive self-care behaviours. These included adherence to medication, dietary and fluid restrictions, and help seeking behaviours (Articles 3; 8). Poor understanding of self-care practices by family members were influenced by culture (Articles 5; 13). In these cultures, self-management programmes are considered as stepping out of the norm and could lead to social isolation (Article 3); being a burden on family is perceived as an inevitable ending of such an adherence (Article 5).

Our results would further suggest that knowledge of heart failure symptoms and medications, were given the highest priority on patients' list of "unmet needs" (Articles 1; 3; 12). Primarily, for their direct and clear correlation with poor functionality and quality of life. Also, patients' self-management decisions and actions were consequently based on changes in symptom severity. However, patients' ability to recognise and evaluate change in symptoms were often low due to the subjective way they monitored symptoms (Article 3). For example, reporting dyspnoea as "too much pressure" or "losing breath". This subjective monitoring was affected by culture and led to poor and delayed actions such as delayed help-seeking behaviours.

Help seeking decisions are also based on patients' unique experience and knowledge and are easier to make and adhere to if they're consistent with cultural beliefs (Articles 3; 5; 8; 12; 13).

Most studies have recommended identifying more culturally appropriate interventions to increase knowledge (Article 1;2;6;10), reduce readmissions and cardiovascular deaths (Article 7), to facilitate self-care and enhance compliance (Article 1;3;5;8;11;13) and for better dyadic emotional, psychological, and coping support (Article 2;4;6;7;12). Our finding suggests that interventions were tailored based on the Western culture (Article 5;10;13) and implemented worldwide. These interventions need to be culturally customised before being implemented for the cultural groups residing in the western countries. Although, these groups do, to a certain extent, adapt to their host cultures, decisions regarding self-care are often driven by their original cultural beliefs (Article 1;2;3;6;7;8;12). There is reasonable evidence that interventions in which appropriate cultural modifications are applied, indicate better health outcomes. For instance, Article 7 provided evidence of effectiveness of programmes that fit with cultural beliefs and provided by trained registered nurses to patients and family members using interactive teaching techniques.

5. Discussion

This mixed-methods review identified three constructed themes on the influence of culture on the understanding of advanced heart failure. These themes were examined through a theoretical lens. The PEN-3 model was utilised and served as a tool to assess, analyse and synthesise the cultural impacts according to patients' and family members' understanding of heart failure across different cultures (Table 3). This study was challenging since our broad search strategy retrieved only 13 relevant articles, none of which directly addressed directly the cultural understanding of heart failure.

All studies, however, investigated the effects of cultural beliefs on patients' and/or family members' understanding of heart failure. However, none of them explicitly explored the understanding of health care professionals. These cultural insights could be critical to allow the development of complex interventions to overcome obstacles triggered by cultural misconceptions. Furthermore, a lack of consistency in methodological rigour was found across many studies, including in tool utilisation, data analysis methods and even the definition of culture, as a universal consensus on this definition is not available.

We found people from non-Western cultures, both living in a Western country or in their original country, are more likely to have a distorted understanding of heart failure because of the cultural ideas and beliefs that have been passed down through generations. People in modern, or Western cultures, who adopt biomedical ideologies, are also more likely to thrive on change (Ibeneme, Eni, Ezuma, & Fortwengel, 2017; Lip et al., 2004; Pattenden et al., 2007). Often, traditional cultures believe that faith, religion, and culture are integrated and intertwined, and culture and technology have always been interconnected. Patients were, therefore, accepting of their fate because of their cultural inherent faith in healthcare (Truitt & Verdial, 2017).

Our findings suggest that lay knowledge of heart failure diagnosis, causes, treatment and self-management is predominately influenced by cultural context. From a qualitative perspective, the impact of culture on lay knowledge was cumulative, starting early and occurring at every stage of heart failure trajectory until its advanced stages. Each culture shares a specific set of interwoven values, beliefs and behaviours that influence patients and families' understanding of advanced heart failure. Patients from non-Western cultures were keen to control their condition and to seek health services when necessary, if this was compatible with their beliefs. However, due to the absence of culturally competent services they were compelled to seek help from their system of cultural health beliefs. Some of these beliefs limited their perceived control over their condition, which may lead to further ineptitude in managing healthy behaviours i.e. help-seeking. In summary, neither patients nor their families were readily prepared for the advanced stage of their illness and end of life care. This problem occurred across all studies irrespective of study designs, country, setting and date.

An understanding of heart failure is a pre-requisite for better management across the trajectory of the condition (Sobanski et al., 2019). Despite the recent universal focus on heart failure, people are still relying on culturally informed lay knowledge and understanding of heart failure. This review found little empirical evidence of this lay knowledge and no articles considered the correlation between lay knowledge and culture. Researchers have, however, investigated lay knowledge to understand non-compliant behaviours adopted by people when they are ill (Popay & Williams, 1996; Rosenstock, 1974), and more recently, there has been a growing recognition of the concept of lay knowledge within research (Rabeharisoa, Moreira, & Akrich, 2014), especially in medical sociology.

This review contradicts in principle Namukwaya et al. (2017) who claimed that lay knowledge of heart failure definitions, symptoms and the use of folk medicine are derived from patient cultural contexts. Our findings are broadly in line with the evidence from the heart failure 'initiative' campaign, where misconceptions and cultural misbeliefs led most people to ignore and perceive symptoms as age-related (Störk et al., 2016). A similar conclusion was reached by others who assert that cultural health beliefs, from caregivers' perspectives, do not only influence heart failure lay knowledge and understanding, but also create it. Nevertheless, family caregiving is seen as an embedded norm in life and culture in many non-Western cultures (M. L. Fang, Sixsmith, Sinclair, & Horst, 2016; Grant & Graven, 2018).

Our synthesis is consistent with a previous meta-analysis and reviews which explored the influences of cultural and familial beliefs on heart failure self-care (Attaallah, Klymko, & Hopp, 2016; De Geest et al., 2004; Horne et al., 2013; Sebern & Riegel, 2009; Shahin, Kennedy, & Stupans, 2019). Culturally sensitive clinical management depends on the degree of understanding of clinicians of patients' cultural beliefs and values (McQuaid & Landier, 2018).

Cultural beliefs and norms may influence the understanding and the expression of symptoms. This interpretation is directly in line with previous findings by (Zhou et al., 2016). However, our findings contradict conclusions from Moser et al. (2014) and Park and Johantgen (2017) on symptom clustering. This may be because of the latter's use of a more advanced analysis technique and symptom intensity-based labelling. Both have utilised a customised set of subscales of the original Minnesota Living with Heart Failure Questionnaire (MLHFQ) tool. This may have compromised the validity of the tool and the reliability of findings as the reduced symptoms may be equally important to patients despite the enhanced readability of the utilised tool. In addition, the removal

of items such as “difficulty walking or climbing” was neither discussed nor justified. It remains unclear to which degree symptom clustering are attributed to cultural, ethnical or societal factors. In parallel with DeVon et al. (2017), we believe that more attention should be paid to understand how symptoms cluster cross culturally

Another significant finding from our review relates to heart failure self-care. When discussing patients’ understanding of heart failure self-care in different cultural contexts, it is imperative to understand their unique lifestyle and dietary patterns and traditions. The data implies that many cultures were neither motivated nor provided the necessary skills and knowledge for self-care. Although the majority believed that some of their cultural beliefs led them to poorly self-manage health, they did not agree the westernised way of living to be the solution. This gap would be best addressed by culturally competent heart failure interventions that could enhance understanding of self-care and related behaviours, increase service satisfaction and ultimately, improve their health-related outcomes. In addition, lay beliefs about heart failure were misleading in terms of symptom recognition, so it is not realistic to expect proper engagement in self-care.

The narratives of poor adherence to self-care, such as adherence to medication, may be due to communications pitfalls and can be attributed to cultural differences. Therefore, a disparity between the person’s cultural understanding and clinician understanding may lead them to neglect medications or other healthcare recommendations. In addition to, the family members being neither empowered not kept in the loop of treatment or conversation. There is a global consensus on the vital role of specialist palliative care to deploy these critiques by proper addressing of the patient and their family members (Sobanski et al., 2019; WHO, 2016). Patients from non-Western cultures seek healthcare consultations for more serious or life-

threatening illnesses when their traditional treatment fails or when their symptoms become worse (Jiang et al., 2013; Namukwaya et al., 2017; Rong et al., 2017). Cultural consideration when developing an intervention should, therefore, embrace patients' language, social context and role of family, and patient values and beliefs about disease to be viable and bridge the gap.

6. Limitations

There are a few limitations identified during this synthesis. The review was predominately qualitative, which reflects the recent but growing interest in this subject, globally. Qualitative inquiries are beneficial as a starting point to explore a new phenomenon, but the subjective nature of this type of enquiry also carries risk of bias and may compromise the transferability of findings. Moreover, the majority of data were collected in hospitals and so may not be representative of the general population. The low sample sizes of the primary studies may also reduce the generalisability of the results.

Additionally, the searches were limited to English-language articles which will exclude some of the literature from non-Western non-English-speaking cultures, especially from countries across Asia and South America.

Research in this field is difficult as the impact of culture is hard to measure; thus, drawing definitive conclusions and provide recommendations for better cultural care provision solely from the reports included here is problematic, This is still an area warranting further in-depth inquiry.

7. Conclusion

The purpose of this review is to explore how culture influences the understanding of advanced heart failure for patients and their family members, and how culture influences the adoption of healthy behaviours.

It is apparent that there is much complexity surrounding the effect of culture on the understanding of advanced heart failure and, therefore, heart failure related decisions and behaviours. Particularly among non-Western patients, the role of culture is crucial to the understanding of heart failure and its management. Patients' perception of the severity of their heart failure is primarily based on the severity of the symptoms. Patients act when their symptoms became severe, or worsen, based on the symptoms' perceived intensity and its cultural interpretations. Patients with heart failure who hold non-Western cultural beliefs were more likely to avoid or delay seeking healthcare services, and we found that this was because of their lay knowledge and understanding of heart failure diagnosis, causation, symptoms and treatment, coupled with other socio-economic barriers.

Cultural competency is central to patient-centred care and could be achieved by the development and the implementation of interventions to support healthcare providers to provide safe and high-quality care for diverse patient groups and their families in a culturally sensitive fashion. These interventions should be tailored according to the lay understanding of heart failure to maximise the benefit and cultural relevance of health messages and, therefore, their impact on peoples' knowledge and behaviours. The findings of the cultural impact on the understanding of advanced heart failure go some way to explain the delayed presentation of patients with heart failure and the under use of palliative care cardiology services.

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9. Tables and Figures

Table 1 Selected articles

Article no.	Author (date); Country	Methodology	Data collection Methods	Sampling	Sample No. (Male/Female)	NHYA class	MMAT
1	Artinian et al. (2002); USA	Descriptive correlational	Investigator-designed questionnaire for sociodemographic data, a 4-points self-rated NYHA scale for severity and a 5-points self-perceived health scale, plus a 15-item heart failure knowledge test.	Non-probability (Quota)	123 Pts (89/32)	The total means 2.57±1.25 equal to class III.	Moderate
2	Barg et al. (2017); USA	Grounded theory	Open-ended, semi structured phone interviews with a sample from a previous study. Process not adequately described. Modified grounded theory analysis was employed.	Purposive	39 Pts (32/7) 42 CGs (9/33)	III & IV; 100%	Moderate

3	Dickson et al. (2013); USA	Mixed-Methods	Concurrent nested design employed using semi-structured guided interviews, standardised instrument and self-report surveys for sociodemographic data. Qualitative gives weight than quantitative data; both data collected simultaneously.	Purposive	30 Pts(18/12)	III; 67%	Moderate
4	Etemadifar et al. (2015); Iran	descriptive, exploratory qualitative	Semi structure interviews were utilised and conducted according to patients' preferences. Field notes documented based on researchers' observations. Study adopted an inductive approach and data collection continued until full saturation, when no new threads emerged.	Purposive	21 CGs(5/16)	NS	Moderate

5	Jiang et al. (2013); Taiwan	Phenomenological	Semi-structured in-depth interviews conducted by the in a cardiac ward post-discharge. CGs interviewed when possible; however, in the case of disagreement patients' words preferred.	Purposive	12 Pts (8/4)	NS* (frequent rehospitalisation and Pts on fluid restrictions)	Low
6	Lip et al. (2004); UK	Cross-sectional	Questionnaire-based interviews conducted after initial pilot. Three researchers interviewed patients in English, Urdu, Punjabi and Hindi. Interviews conducted in standardised way, as far as possible.	Consecutive	103 Pts (66/37)	III &IV; 62.2%	Moderate

7	Mau et al. (2017); Hawaii	Randomised controlled trial	Three health behaviour questionnaires used at baseline and after 12-month follow-up: 23-item Kansas City Cardiomyopathy Questionnaire, 10-item Centre for Epidemiological Studies of Depression Scale; 12-item Health Survey.	Randomised	150 Pts (103/47)	III; 11%, IV; 48%	High
8	McCarthy et al. (2015); USA	Mixed-methods	Sequential transformative design study. Quantitative part collected first using Self Care Heart Failure Index, Duke Activity Status Index, Patient Health Questionnaire and standardised survey to estimate heart failure severity. Data collected qualitatively through open-ended, semi-structured interviews.	Convenience Secondary analysis of Dickson et al. (2013)	30 Pts(18/12)	III; 65%	Moderate

9	Moser et al. (2014); USA, China, Taiwan, Netherlands, and Sweden	Observational	Interviews for sociodemographic data, clinical data collected from medical records; symptoms identified using Minnesota Living with Heart Failure Questionnaire.	Purposive	720 Pts (455/265)	III &IV; 69.9%	Moderate
10	Namukwaya et al. (2017); Uganda	Constructivist grounded theory	Serial qualitative in-depth interviews, three times at 3 month intervals; interview consists of 9 open-ended questions with multiple prompts.**	Purposive	21 Pts (6/13)	III &IV; 100%	Moderate

11	Park and Johantgen (2016); USA vs. China and Taiwan	Cross-sectional, observational	All participants who have completed all symptom inventories in terms of symptom reporting and clusters were included in the study.***	Secondary analysis of Moser et al. (2014).	480 Pts (308/172)	III; 48.5% IV; 23.5%	Moderate
12	Pattenden et al. (2007); UK	Phenomenological Qualitative study	Semi-structured interviews were conducted in patients' homes by a qualified, bi-lingual researcher. 60% were interviewed with CGs. Patients and CGs had separate sets of questions. Interview notes were taken by the same researcher during and after each interview. An interpreter attended one interview.	Purposive	36 Pts (23/13) 20 CGs (2/18)	III; 36% IV; 22%	High

13	Rong et al. (2016); China	Descriptive qualitative	Semi structured interviews were conducted for 30–60 minutes until full saturation. All sessions took place in an accessible room in the cardiac ward.	Purposive	15 Pts (9/6)	III; 40% IV; 20%	Moderate

Legend:

*Fluid restrictions are only recommended for patients with severe heart failure (European Society 2012).

**These questions were used in a larger study which also aimed at understanding patients' beliefs about heart failure and its treatment.

***A ready data set was provided by the first and corresponding author Dr. Debra Moser. For more details, see Moser et al. 2014 above.

CG: Caregivers; CR: Cardiac Rehabilitation; LVAD-DT: Left Ventricular Assisted Device-Destination Therapy; MMAT: Mixed Methods Appraisal Tool; MPP: Mālama Pu'uwai Programme.; NHOPI: Native Hawaiian and Other Pacific Islanders; NS: Not Stated; NYHA: New York Heart Association; PA: Physical Activity; Pts: patients,; TCM: Traditional Chinese Medicine.

Table 2 Data extraction summary of the cultural impact outcomes.

Author (date)/ Country	**Population Focus**	**The impact of culture on**
Artinian et al. (2002)/ USA	African American communities	Culture and related sociodemographic factors inform patients' lay heart failure self-care knowledge of and adherence to.
Barg et al. (2017)/ USA	LVAD-DT community (European American, Native American and African American)	This cultural appreciation of the use of technology in healthcare affects patients' perceived control over treatment preferences and decisions
Dickson et al. (2013)/ USA	African American community	The culture endorses supernatural assumptions as a cause of heart failure, which limit the perceived control over health and motivation toward healthy self-care practices.
Etemadifar et al. (2015)/ Iran	Persian CGs community	Carers lack clear understanding of heart failure and rely on lay cultural beliefs. They believe in religion and culture as the main source of knowledge due to perceived role ambiguity.

Jiang et al. (2013)/ Taiwan	Older Chinese/ Taiwanese community	Patients were bound to cultural beliefs on food, medicinal products, exercise intolerance and the importance of family more than the health recommendations provided. Also, culture implies barriers to asking or interacting with clinicians.
Lip et al. (2004)/UK	Multi-ethnic, multicultural communities including white European, Indo-Asian and Afro-Caribbean,	Ethnic, cultural and religious beliefs are guiding patient perception of heart failure and its treatments. This result in the majority of patients lack clear understanding of disease including symptoms, perceived control over patients' condition and adherence to treatment.
Mau et al. (2017)/Hawaii	NHOPI communities	Health education programmes has positive outcomes on the understanding of heart failure, morbidity and mortality when it is consistent with cultural beliefs and provided by trained staff in a sensitive fashion.

McCarthy et al. (2015)/ USA	African American community	Exercise was defined based on patients' cultural context, which led the majority of patient to refuse taking part in cardiac rehabilitation programmes, particularly among those living in low socioeconomic levels.
Moser et al. (2014)/ USA, China, Taiwan, Netherlands, and Sweden	Western (US & Europe) vs. Eastern (Asian) communities	Understanding symptom, symptom experience, reporting and clustering were consistent across different cultures.
Namukwaya et al. (2017)/Uganda	Kampala Communities, Uganda	Cultural context is informing health beliefs, decisions and behaviours.
Park & Johantgen (2016)/ USA vs. China & Taiwan	Western vs. Eastern communities	Eastern patients have the same order of the distress code of the symptoms. However, they have delayed symptom reporting, less ability to recognise the change in psychological symptoms and underestimated severity of disease compared to patients from western backgrounds.

Pattenden et al. (2007)/ UK	Patients and caregivers of South Asian origin living in rural and urban Scottish &Irish communities.	Culture is responsible for the formation of most of health beliefs and behaviours. This role also applies for people who have immigrate from eastern to western cultures.
Rong et al. (2016)/ China	Older Chinese communities	Chinese patients are unable to adhere to dietary and fluid restrictions due to their contradiction with innate cultural beliefs and religion. Culturally influenced beliefs should not be ignored particularly among older generations living in low economic levels.

Abbreviations- CG: Caregivers, NS: Not Stated, TCM: Traditional Chinese Medicine, LVAD-DT: Left Ventricular Assisted Device-Destination Therapy, PA: Physical Activity, CR: Cardiac Rehabilitation, NHOPI: Native Hawaiian and Other Pacific Islanders, MPP: Mālama Pu‘uwai Programme.

Table 3 Modified PEN-3 Model crosstabulation analysis

2nd domain (Relationships &expectations)	**Theme**	**3rd Domain (cultural empowerment)**		
		Positive	Existential	Negative
Perceptions (Cultural values and beliefs held by people about	The understanding of symptoms,	Physical symptoms are top priority. Symptoms when developed quickly and intensely should be	The ranking orders of physical symptoms.	- Eastern patients had significantly lower perceived severity of disease and sensitivity to psychological symptoms.

	reporting and clustering.	reported as it reflects heart failure exacerbation.		- Subjective understanding of symptoms and its severity. - The reported symptoms need to be confirmed and consistent with being severe as defined by the community.
	Lay heart failure knowledge and beliefs.	Common understanding was relatively uniformed within each culture	lack of knowledge	- Cultural non-biomedical understanding of heart failure definition, its causes and treatment. - Poor health literacy. - Experience-based knowledge including self-care. - Misconceptions about heart failure and new treatments. - The perception of supernatural power in developing diseases, low perceived control over their condition and the perceived superiority of traditional healers, food and medicine.

				- Role ambiguity and caregiver uncertainty when providing care. - Perceived family burden if they follow dietary advices.
	Understanding of heart failure Self-care.	- Accepting illness and positive attitudes toward treatment if consistent with the cultural definition of disease. - The family is responsible for the health, wellbeing and follow up of its members	The history of living healthy and active lifestyle.	- Patients don't comply with treatment regimen i.e. skipping medication if no symptoms - Misconceptions about self-care practices i.e. exercise was believed to be impossible with heart failure because it worsens symptoms. - Misunderstanding the benefit of cardiac diet and the preference of traditional unhealthy food.
		Positive	**Existential**	**Negative**

Enabler/Barriers. **(The impact of systems-level factors, which could facilitate or impede any change i.e. help seeking behaviour)**	Relationship between cultures and adopt healthy behaviour such as help-seeking.	- The availability resources such as a wide range of healthy food and medicine, westernised as well as traditional. - Social support and kinship. - Healthcare system when responsive to patients' unique cultural needs		- The low socioeconomic status, costly healthy food and health checks. - Emphasising on the importance of family and social kinship and social gathering more than health. - Lack of system combining western with traditional medicine. - No regular health checks and follow ups unless if seriously ill - Healthcare advices being culturally incompetent.
		Positive		**Negative**

Nurturer **(The impact of social support and its role in changing health behaviour.**		- The embeddedness of caring role. - Family and friends support patient's health and wellbeing. - Family and friends understanding of heart failure and the importance of balanced food and healthy living during the course of illnesses. - Friends: good resource for valuable advice.	- Food etiquette and family members being burdened preparing different meals for patients. - The suboptimal understanding of family and - friends of heart failure and self-care. - Inconsiderate healthcare system to family members and the lack of cultural competence in health system and information mainly about self-care.